108TH CONGRESS
2D SESSION

S. _____

IN THE SENATE OF THE UNITED STATES

Mr. NELSON of Florida introduced the following bill; which was read twice and referred to the Committee on _____

A BILL

To amend titles XVIII and XIX of the Social Security Act and title III of the Public Health Service Act to improve access to information about individuals' health care options and legal rights for care near the end of life, to promote advance care planning and decisionmaking so that individuals' wishes are known should they become unable to speak for themselves, to engage health care providers in disseminating information about and assisting in the preparation of advance directives, which include living wills and durable powers of attorney for health care, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the ''Advance Directives Improvement and Education Act of 2004''.

(b) TABLE OF CONTENTS.—The table of contents of this Act is as follows:

SEC. 2. FINDINGS AND PURPOSES.

(a) FINDINGS.—Congress makes the following findings:

(1) Every year 2,500,000 people die in the United States. Eighty percent of those people die in institutions such as hospitals, nursing homes, and other facilities. Chronic illnesses, such as cancer and heart disease, account for 2 out of every 3 deaths.

(2) In January 2004, a study published in the Journal of the American Medical Association concluded that many people dying in institutions have unmet medical, psychological, and spiritual needs. Moreover, family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.

(3) In 1997, the Supreme Court of the United States, in its decisions in Washington v. Glucksberg and Vacco v. Quill, reaffirmed the constitutional right of competent adults to refuse unwanted medical treatment. In those cases, the Court stressed the use of advance directives as a means of safeguarding that right should those adults become incapable of deciding for themselves.

(4) A study published in 2002 estimated that the overall prevalence of advance directives is between 15 and 20 percent of the general population, despite the passage of the Patient Self-Determination Act in 1990, which requires that health care providers tell patients about advance directives.

(5) Competent adults should complete advance care plans stipulating their health care decisions in the event that they become unable to speak for themselves. Through the execution of advance directives, including living wills and durable powers of attorney for health care according to the laws of the State in which they reside, individuals can protect their right to express their wishes and have them respected.

(b) PURPOSES.—The purposes of this Act are to improve access to information about individuals' health care

options and legal rights for care near the end of life, to promote advance care planning and decisionmaking so that individuals' wishes are known should they become unable to speak for themselves, to engage health care providers in disseminating information about and assisting in the preparation of advance directives, which include living wills and durable powers of attorney for health care, and for other purposes.

SEC. 3. MEDICARE COVERAGE OF END-OF-LIFE PLANNING CONSULTATIONS.

(a) COVERAGE.—Section 1861(s)(2) of the Social Security Act (42 U.S.C. 1395x(s)(2)), as amended by section 642(a) of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Public Law 108–173; 117 Stat. 2322), is amended—

(1) in subparagraph (Y), by striking ''and'' at the end;

(2) in subparagraph (Z), by inserting ''and'' at the end; and

(3) by adding at the end the following new subparagraph:

''(AA) end-of-life planning consultations (as defined in subsection (bbb));''.

(b) SERVICES DESCRIBED.—Section 1861 of the Social Security Act (42 U.S.C. 1395x), as amended by sec-

tion 706(b) of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Public Law 108–173; 117 Stat. 2339), is amended by adding at the end the following new subsection:

''End-of-Life Planning Consultation

''(bbb) The term 'end-of-life planning consultation' means physicians' services—

''(1) consisting of a consultation between the physician and an individual regarding—

''(A) the importance of preparing advance directives in case an injury or illness causes the individual to be unable to make health care decisions;

''(B) the situations in which an advance directive is likely to be relied upon;

''(C) the reasons that the development of a comprehensive end-of-life plan is beneficial and the reasons that such a plan should be updated periodically as the health of the individual changes;

''(D) the identification of resources that an individual may use to determine the requirements of the State in which such individual resides so that the treatment wishes of that individual will be carried out if the individual is un-

able to communicate those wishes, including requirements regarding the designation of a surrogate decision maker (health care proxy); and

''(E) whether or not the physician is willing to follow the individual's wishes as expressed in an advance directive; and

''(2) that are furnished to an individual on an annual basis or immediately following any major change in an individual's health condition that would warrant such a consultation (whichever comes first).''.

(c) WAIVER OF DEDUCTIBLE AND COINSURANCE.—

(1) DEDUCTIBLE.—The first sentence of section 1833(b) of the Social Security Act (42 U.S.C. 1395*l*(b)) is amended—

(A) by striking ''and'' before ''(6)''; and

(B) by inserting before the period at the end the following: '', and (7) such deductible shall not apply with respect to an end-of-life planning consultation (as defined in section 1861(bbb))''.

(2) COINSURANCE.—Section 1833(a)(1) of the Social Security Act (42 U.S.C. 1395*l*(a)(1)) is amended—

(A) in clause (N), by inserting ''(or 100 percent in the case of an end-of-life planning consultation, as defined in section 1861(bbb))'' after ''80 percent''; and

(B) in clause (O), by inserting ''(or 100 percent in the case of an end-of-life planning consultation, as defined in section 1861(bbb))'' after ''80 percent''.

(d) PAYMENT FOR PHYSICIANS' SERVICES.—Section 1848(j)(3) of the Social Security Act (42 U.S.C. 1395w–4(j)(3)), as amended by section 611(c) of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Public Law 108–173; 117 Stat. 2304), is amended by inserting ''(2)(AA),'' after ''(2)(W),''.

(e) FREQUENCY LIMITATION.—Section 1862(a)(1) of the Social Security Act (42 U.S.C. 1395y(a)(1)), as amended by section 613(c) of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Public Law 108–173; 117 Stat. 2306), is amended—

(1) by striking ''and'' at the end of subparagraph (L);

(2) by striking the semicolon at the end of subparagraph (M) and inserting '', and''; and

(3) by adding at the end the following new subparagraph:

''(N) in the case of end-of-life planning consultations (as defined in section 1861(bbb)), which are performed more frequently than is covered under paragraph (2) of such section;''.

(f) EFFECTIVE DATE.—The amendments made by this section shall apply to services furnished on or after January 1, 2005.

SEC. 4. IMPROVEMENT OF POLICIES RELATED TO THE USE AND PORTABILITY OF ADVANCE DIRECTIVES.

(a) MEDICARE.—Section 1866(f) of the Social Security Act (42 U.S.C. 1395cc(f)) is amended—

(1) in paragraph (1)—

(A) in subparagraph (B), by inserting ''and if presented by the individual (or on behalf of the individual), to include the content of such advance directive in a prominent part of such record'' before the semicolon at the end;

(B) in subparagraph (D), by striking ''and'' after the semicolon at the end;

(C) in subparagraph (E), by striking the period at the end and inserting ''; and''; and

(D) by inserting after subparagraph (E) the following new subparagraph:

''(F) to provide each individual with the opportunity to discuss issues relating to the information

provided to that individual pursuant to subparagraph (A) with an appropriately trained professional.'';

(2) in paragraph (3), by striking ''a written'' and inserting ''an''; and

(3) by adding at the end the following new paragraph:

''(5)(A) In addition to the requirements of paragraph (1), a provider of services, Medicare Advantage organization, or prepaid or eligible organization (as the case may be) shall give effect to an advance directive executed outside the State in which such directive is presented, even one that does not appear to meet the formalities of execution, form, or language required by the State in which it is presented to the same extent as such provider or organization would give effect to an advance directive that meets such requirements, except that a provider or organization may decline to honor such a directive if the provider or organization can reasonably demonstrate that it is not an authentic expression of the individual's wishes concerning his or her health care. Nothing in this paragraph shall be construed to authorize the administration of medical treatment otherwise prohibited by the laws of the State in which the directive is presented.

''(B) The provisions of this paragraph shall preempt any State law to the extent such law is inconsistent with such provisions. The provisions of this paragraph shall not preempt any State law that provides for greater portability, more deference to a patient's wishes, or more latitude in determining a patient's wishes.''.

(b) MEDICAID.—Section 1902(w) of the Social Security Act (42 U.S.C. 1396a(w)) is amended—

(1) in paragraph (1)—

(A) in subparagraph (B)—

(i) by striking ''in the individual's medical record'' and inserting ''in a prominent part of the individual's current medical record''; and

(ii) by inserting ''and if presented by the individual (or on behalf of the individual), to include the content of such advance directive in a prominent part of such record'' before the semicolon at the end;

(B) in subparagraph (D), by striking ''and'' after the semicolon at the end;

(C) in subparagraph (E), by striking the period at the end and inserting ''; and''; and

(D) by inserting after subparagraph (E) the following new subparagraph:

''(F) to provide each individual with the opportunity to discuss issues relating to the information provided to that individual pursuant to subparagraph (A) with an appropriately trained professional.'';

(2) in paragraph (4), by striking ''a written'' and inserting ''an''; and

(3) by adding at the end the following paragraph:

''(6)(A) In addition to the requirements of paragraph (1), a provider or organization (as the case may be) shall give effect to an advance directive executed outside the State in which such directive is presented, even one that does not appear to meet the formalities of execution, form, or language required by the State in which it is presented to the same extent as such provider or organization would give effect to an advance directive that meets such requirements, except that a provider or organization may decline to honor such a directive if the provider or organization can reasonably demonstrate that it is not an authentic expression of the individual's wishes concerning his or her health care. Nothing in this paragraph shall be construed to authorize the administration of medical treatment otherwise prohibited by the laws of the State in which the directive is presented.

''(B) The provisions of this paragraph shall preempt any State law to the extent such law is inconsistent with such provisions. The provisions of this paragraph shall not preempt any State law that provides for greater portability, more deference to a patient's wishes, or more latitude in determining a patient's wishes.''.

(c) EFFECTIVE DATES.—

(1) IN GENERAL.—Subject to paragraph (2), the amendments made by subsections (a) and (b) shall apply to provider agreements and contracts entered into, renewed, or extended under title XVIII of the Social Security Act (42 U.S.C. 1395 et seq.), and to State plans under title XIX of such Act (42 U.S.C. 1396 et seq.), on or after such date as the Secretary of Health and Human Services specifies, but in no case may such date be later than 1 year after the date of enactment of this Act.

(2) EXTENSION OF EFFECTIVE DATE FOR STATE LAW AMENDMENT.—In the case of a State plan under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) which the Secretary of Health and Human Services determines requires State legislation in order for the plan to meet the additional requirements imposed by the amendments made by subsection (b), the State plan shall not be regarded

as failing to comply with the requirements of such title solely on the basis of its failure to meet these additional requirements before the first day of the first calendar quarter beginning after the close of the first regular session of the State legislature that begins after the date of enactment of this Act. For purposes of the previous sentence, in the case of a State that has a 2-year legislative session, each year of the session is considered to be a separate regular session of the State legislature.

SEC. 5. INCREASING AWARENESS OF THE IMPORTANCE OF END-OF-LIFE PLANNING.

Title III of the Public Health Service Act is amended by adding at the end the following new part:

"PART R—PROGRAMS TO INCREASE AWARENESS OF ADVANCE DIRECTIVE PLANNING ISSUES

"SEC. 399Z–1. ADVANCE DIRECTIVE EDUCATION CAMPAIGNS AND INFORMATION CLEARINGHOUSES.

''(a) ADVANCE DIRECTIVE EDUCATION CAMPAIGN.—The Secretary shall, directly or through grants awarded under subsection (c), conduct a national public education campaign—

''(1) to raise public awareness of the importance of planning for care near the end of life;

''(2) to improve the public's understanding of the various situations in which individuals may find themselves if they become unable to express their health care wishes;

''(3) to explain the need for readily available legal documents that express an individual's wishes, through advance directives (including living wills, comfort care orders, and durable powers of attorney for health care); and

''(4) to educate the public about the availability of hospice care and palliative care.

''(b) INFORMATION CLEARINGHOUSE.—The Secretary, directly or through grants awarded under subsection (c), shall provide for the establishment of a national, toll-free, information clearinghouse as well as clearinghouses that the public may access to find out about State-specific information regarding advance directive and end-of-life decisions.

''(c) GRANTS.—

''(1) IN GENERAL.—The Secretary shall use at least 60 percent of the funds appropriated under subsection (d) for the purpose of awarding grants to public or nonprofit private entities (including States or political subdivisions of a State), or a consortium of any of such entities, for the purpose of conducting

education campaigns under subsection (a) and establishing information clearinghouses under subsection (b).

''(2) PERIOD.—Any grant awarded under paragraph (1) shall be for a period of 3 years.

''(d) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section $25,000,000.''.

SEC. 6. GAO STUDIES AND REPORTS ON END-OF-LIFE PLANNING ISSUES.

(a) STUDY AND REPORT ON COMPLIANCE WITH ADVANCE DIRECTIVES AND OTHER ADVANCE PLANNING DOCUMENTS.—

(1) STUDY.—The Comptroller General of the United States shall conduct a study on the effectiveness of advance directives in making patients' wishes known and honored by health care providers.

(2) REPORT.—Not later than the date that is 18 months after the date of enactment of this Act, the Comptroller General shall submit to Congress a report on this study conducted under paragraph (1) together with recommendations for such legislation and administrative action as the Comptroller General determines to be appropriate.

(b) STUDY AND REPORT ON ESTABLISHMENT OF NATIONAL ADVANCE DIRECTIVE REGISTRY.—

(1) STUDY.—The Comptroller General of the United States shall conduct a study on the implementation of the amendments made by section 3 (relating to medicare coverage of end-of-life planning consultations).

(2) REPORT.—Not later than 2 years after the date of enactment of this Act, the Comptroller General shall submit to Congress a report on this study conducted under paragraph (1) together with recommendations for such legislation and administrative action as the Comptroller General determines to be appropriate.

(c) STUDY AND REPORT ON ESTABLISHMENT OF NATIONAL ADVANCE DIRECTIVE REGISTRY.—

(1) STUDY.—The Comptroller General of the United States shall conduct a study on the feasibility of a national registry for advance directives, taking into consideration the constraints created by the privacy provisions enacted as a result of the Health Insurance Portability and Accountability Act.

(2) REPORT.—Not later than 18 months after the date of enactment of this Act, the Comptroller General shall submit to Congress a report on this

study conducted under paragraph (1) together with recommendations for such legislation and administrative action as the Comptroller General determines to be appropriate.